

Mark Your Calendar

Support Meetings

First Saturday of the Month

When:

November 3, 2012
February 2, 2013

Business Meeting

6 - 7 p.m.

Support Meeting

7 - 9 p.m.

Where:

Beaumont Hospital
Royal Oak Campus
Administration Bldg
Private Dining Room

Special Events:

November 11, 2012



Dine out for Fragile X!
See page 3.

December 1, 2012

FXAM Holiday Party
See page 3.

March 5-6, 2013

Advocacy Day
Washington, D.C.

Fragile X Association of Michigan

313-381-2834

FXAM.org

contact@fxam.org

Three Cheers for...



Mary Beth and Ted - On July 27, at the 13th Annual International Fragile X Conference in Miami, FXAM's own Jeff Cohen presented Mary Beth Langan and Ted Coutilish with the Halstead-Bresnahan Family Award. NFXF presents this award every two years recognizing those who make a profound difference to families affected by Fragile X Syndrome.

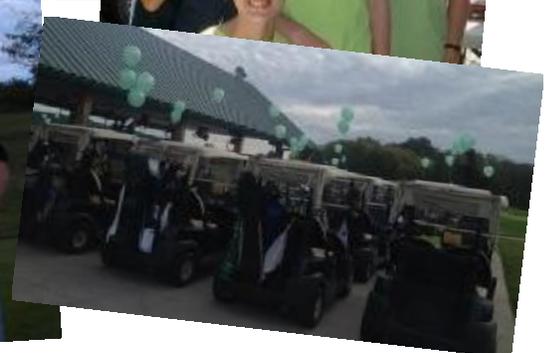
Participants of the Fragile X 5K Fun Run/Walk & Family Picnic

- Jeff and Ryan Roman kick up their heels for Fragile X. Charlie and Amy Lund cross the finish line with Andrew Young close behind.

See page 5.



Golfers for Fragile X across the state



Apps for iDevices (iPhone, iPod, iPad) by Bonnie Korman



Choiceworks

by Bee Visual, LLC (\$9.99)

I have long known the need to have a picture schedule system for my two (currently seven-year-old) boys with Fragile X. I've tried more than once to use handmade PECS pictures, either in a binder or up on a board. The pictures constantly get lost, chewed on, vacuumed, or otherwise mysteriously destroyed. I end up having to make more and more images. I get paper cuts and have recurring nightmares about my fingers being sucked into the laminator.

Then, we got an iPad. And I saw the possibilities. If I could find a good schedule app to use with the boys, I could eliminate the hassle of creating and then losing all those little cards.

Somehow I stumbled upon Choiceworks. I honestly don't remember if it happened to find it in a search in the App Store, or whether I heard about it elsewhere. I follow Moms With Apps and Free App of the Day, so I may have found it through there.

Choiceworks is very simple to use, which is nice if you don't want to spend a great deal of time setting up schedules. And who does? You can

create as many schedule boards as you like. Each schedule board you create will have the same, familiar, vertical layout, with the list of activities on the left and an "all done" column on the right. When my sons complete an activity, they can come over and touch the screen to move the activity over to the "all done" column. Sliding the activities over to the "all done" column is great fun and extremely satisfying for my boys. In fact it's so fun, I have to stop them from going ahead and sliding all the items over to the "all done" column first thing every morning.



There are several aspects of Choiceworks that I really like:

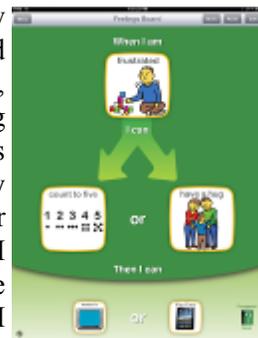
1. Using my own pictures. I love that I can upload my own photos to the app, name them whatever I like, and then use them in the schedules. I had to add images for Target, Doritos, and Grandma and Grandpa right away.
2. Creating as many schedules as I need. I can have a different one for every day of the week. Some days we have speech therapy after school. Some days we drive sister to her dance class. Every day is different, and the changes I have to make are minimal since I can have them set up for each individual day.
3. The number of steps you can put into a schedule is limited to eight. At

first I was annoyed by that, but it turned out to be a very great blessing in disguise. I have a tendency to get bogged down in the details of the day, and when you think about it, can't even the busiest day be simplified to eight small steps? It forced me to break down our days into more general steps, which was good for both the boys and for me.

And if the day can't be planned with only eight images, you could have a "Morning" schedule, an "Afternoon" and an "Evening."

And as far as that goes, you could have a special schedules for trips to the dentist, cleaning up a bedroom, getting dressed, going to church - just about anything you need to get a child through in a day.

Choiceworks has two other types of boards you can personalize - Feelings boards, for describing how a child is feeling and how to cope, and Waiting boards, for planning specific activities to keep busy while waiting for something. I haven't made use of those boards. I can see where they might come in handy someday, and I don't rule out ever using them. I just haven't made that part of our routine. But the schedule boards do go a long way toward helping my boys see the process of our routines and get through them step by step.



Bonnie Korman is the LINKS leader of Fragile X of Minnesota. She's the mother of three children, including twin boys with Fragile X. In her spare time, she blogs about life including Fragile X at www.fragilexfiles.com.

From the President's Desk by Lauren Majeske



There is a chill in the air, but not for us! FXAM is on fire! In August we had a great turnout for our 5K and family picnic. It sprinkled a little and then cleared up for a great day. Lots of new faces this year, we loved meeting you! Thanks to Kim Young for all of your hard work.

September brought us our annual golf fundraiser hosted by the Liberatis. We had a full roster this year, with only room enough for one or two more teams; (Register early next year) this event filled up fast this year. The weather was great, the people are always wonderful, and we had some really great prizes. It doesn't get any better than this, and to top it off, we raised over \$17,000! We appreciate all of our supporters; we couldn't do it without you. SO many families are helped during the year; your money is put to good use! The Hansen family also hosted their

own annual Kent City golf outing. Some of us went up to golf with them and it was a super fun time! They have lots of fun games and prizes at the holes. Trying to hit the row boat in the middle of the lake is ADDICTING. I just know I'll hit it next year! And hot chili out on the course - what a brilliant idea on a cool day! Thanks so much for your support, Hansen family and friends!

And by the time you read this we will have participated in the Healthy Edge Non-Profit Health Expo and What About You Walk at Eastern Michigan University. I can tell you that this is a great event, highly organized by Christie Clipper, along with the talents of our own Ted Coutilish. This year we are giving out "got fragile x?" backpacks to all of the participants and I am looking forward to seeing these orange bags all over campus! Funds from this

event are going to support the fragile x clinic at the University of Michigan. The more we raise, the sooner we'll be able to hire a research coordinator for the clinic and begin having Fragile X drug trials in Michigan.

We are working with Warren Global Conferencing to try to set up a system where you can call into our meetings if you live too far away to attend. We want everyone who needs support to get it! Stay posted for more information. Make sure you're on our email list; contact Mary Beth to be added.

I look forward to seeing you at our next support group meeting on November 3 and at our December 1 FXAM holiday party!

Dine out for Fragile X!

Sunday, November 11, 2012

Dine out with friends and family. Mention Fragile X at the register and 25% goes to FXAM!

Noodles & Company
470 S. Main Street
Royal Oak, MI 48067
248-548-7700

Fundraising hours are from 4 - 9 p.m.
Check out directions, menu and more at noodles.com/RoyalOak

Download the flyer at fxam.org or make copies of the flyer between pages 4 and 5. Share the info with friends, family, colleagues, neighbors, etc via email, Facebook, phone calls, Twitter or a text.

Holiday Party

Annual Potluck Gathering

Saturday, December 1, 2012

5 - 9 pm

Langan-Coutilish Home
Grosse Pointe, MI

More info will arrive via email and FXAM Facebook page or contact Mary Beth at mblangan@hotmail.com or 313-881-3340

If you're not on our email list, please send your email to Mary Beth so you won't miss out on events.

The Thirteenth Annual FXAM Golf Outing

The 13th Annual Fragile X Association of Michigan Golf Outing on September 8 was once again a huge success! The rain stopped a couple of hours before the 116 golfers teed off, so everyone was able to have a great time during the 4-person scramble. Afterwards 140 people enjoyed steaks, potatoes, mostaccioli and side dishes under the tent. Door prizes and raffle items were distributed after dinner. We would like to thank all those who came out to golf, sponsored holes, made donations and all those who helped in setting up, working the par-3 closest-to-the-pin contests and clean up. We couldn't have done it without you!

The Fragile X Association of Michigan continues to be very grateful to **Nina and Frank Liberati** as organizers of this event each year. The 13th Annual Golf Outing raised approximately \$17,500 for the Fragile X cause. Way to go Nina and Frank!

Thank you to everyone who contributed to our success!

The Mickelson (\$1,300+)

Kenwal Steel Corporation
Steven Lebowski
Bob Mannino

The Nicklaus (\$1,000+)

The Palmer (\$500+)

Mike & Stella Banich
Liberty Union
Watson Engineering

The Watson (\$250+)

C. Hawker & Associates
Evelyn Kosch-Mannino
Martin Seward
John & Nancy Warneck

The Player (\$150+)

Adam Holdings LLC
Architectural Door and
Millwork
Arnaldo's Banquet Center
Jerry & Karen Bishop
Blue Marlin II, LLC
Mr & Mrs Dennis Brown

Florence Coleman (In Honor
of Richard)

Commerce Holdings, LLC
Cranbrook Partners and Co.
Dearborn Brand

Green Lantern Pizzeria, LLC
H & L Holdings, LLC

William & Kim Holdsworth
Anthony Iaquinto

International Paper

Father Saylor K of C #3774

Kiwanis Club of Allen Park

Mark Kontry P.C.

Kelly Koson

Lakeshore Utility

Law Offices of Miller &
Miller, PC

Gary & Donna Lebowski

Liberati's Italian Deli & Bakery

Liberati & Sons Construction

Papa & Mama Rose Liberati

Lincoln Park Community

Credit Union

Mascari Sales and

Marketing, LLC

McInerney's Chrysler Dodge

Jeep

Mr. Joe's Sport Bar - Southfield

The Nantais Family

Pia's, Inc.

Pierce & Pierce, PC

Pomponio Construction

Mark & Malinda Popejoy

Preferred Brands

Charlie & Inez Roy

Sue Shannon

Silverton Skin Institute

Mr & Mrs Darcy Smith

Telegraph Chrysler Dodge

Jeep Ram

Theresa Sternicki

UAW - Ford Local 900

Kenneth Vance &

Associates, P.C. James & Cindy

Vickey

Weed Eraser, Inc

Wolff Group, LLC

The Wurth Family

Weed Eraser, Inc

David Wujczyk

The Wurth Family

We would also like to thank the following individuals, businesses and organizations for their donations and/or time dedicated to this event:

Agemy & Sons Market

Anthony Aratari

Bob & Pat Asmussen

Jim & Julie Bademian

Mr & Mrs Malcolm Beaton

Jeffrey Cohen JD, PC

Nick & Kelsey Coleman

Mr. Patrick Duerr, JR

JoAnn Forde

Fraternal Order of Police,

Lodge #110

Lori Friesner

J. Goulasarian Contracting

Chrissy Grybel

Rosalie Guerra

Mr. & Mrs. M. Hall

John & Kate Hansen

Italia Bakery

George & Barbara Jakubik

Levon & Gloria King

Paul Klenczar

Mary Beth Langan

Tony & Maria Lalli

Deborah Lee

M-Den

Len & Peggy Majeske

Tony & Dora Mangiapane

Jeannette McMillan

Jerry & Sally Nantais

The Orchards Golf Club

Jerome & Jeannette Pearsons

Virginio & Anna Reale

Rony's Body Shop, Inc

Susan Stearns

John & Susan Sturock

Lester & Lisa Voutsos

Mitch & Fran Wolski

Weight Watchers

Sheryl Fellows

Judith Zarkis, The Country

Store, Romeo

Fragile X 5K Fun Run/Walk & Family Picnic

All of us living in the fragile X world know all too well about overcoming challenges. The annual Fragile X 5K Run/walk & Family Picnic this past August was no exception! Mother Nature definitely gave us a few weather challenges to overcome. Fortunately, the rain stopped during the run just long enough for us all to breeze through the

wooded trails and return to the shelter for a cozy lunch with friends. Despite the chilly day everyone had a great time and the event was a success.

The Fragile X Association of Michigan would like to extend special thanks to these sponsors:

- Rotpac Racing - for providing our timing for the race every

year at a discount - Rotpac.com

- DVM Enterprises of Linden
- Albaugh Masonry Stone & Tile - Albaumasonry.com

Please think about coming out to join us next summer to enjoy a day of good food, good friends and fun!

"Not what we have but what we enjoy constitutes our abundance."

~ Epicurus (Greek philosopher, BC 341-270)

Through the Maze Featured Websites

Ever feel like reading about how Fragile X is affecting another family's life? There are a number of Fragile X parents who blog, including about how daily life in their homes is affected by Fragile X. For some folks, reading about others on a Fragile X journey helps them feel not so alone and as if others understand their lives.

If this interests you... here are some of the Fragile X-related blogs. Enjoy!

www.fragilexfiles.com

thefascianos.com

ourfxjourney.blogspot.com

mrsrogersfxneighborhood.blogspot.com

basicallyfx.com

lifewithmyxmen.blogspot.com

marcandrachael.blogspot.com

Hansen 6th Annual Fragile X Golf Outing

The Hansen 6th Annual Fragile X Golf Outing was held on September 21 at The Falls at Barber Creek in Kent City, MI. We had 62 golfers and raised approximately \$5,300. This year helium balloons were sold as mulligans. A team could buy up to four. Attached to each balloon was a card with the NFXF logo and their website. When a golfer used a mulligan, the balloon was released up into the air. Just doing our part to spread awareness! :o)

A close friend of Kate Hansen, Cyndi Reed, volunteered 50 hours to the golf outing. In turn, Cyndi's employer, Verizon, will be giving a \$750 grant to FXAM! YAY Cyndi - thank you so much for your hard work and dedication!! And thank you Verizon!!

We were once again blessed by golfers coming from our metro Detroit FXAM family - thank you Nina and Frank Liberati and Laureen Majeske for making the trip. Laureen spoke to the group during lunch and shared info about FXAM and some of the exciting news on the research front.

Thank you Hansen Family!

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FXAM.org



Experimental drug gives hope for rare disease, autism

USA Today - September 20, 2012

For the first time, a drug has shown success in treating social withdrawal symptoms in children with a rare disorder called Fragile X Syndrome, leading scientists to hope that it might also help those with autism. Read the whole story at

<http://www.usatoday.com/news/nation/story/2012/09/20/fragile-x-and-autism/57808848/1>

Progress in Identifying the Genetic Roots of Autism

The Wall Street Journal - September 24, 2012

One of the most agonizing questions that parents of children with autism ask is—why? Now, a growing number of genetic tests are providing some answers. Scientists say that roughly 20% of autism cases can be linked to known genetic abnormalities, and many more may be discovered. Read more at:

<http://online.wsj.com/article/SB10000872396390444813104578016280501020620.html>

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